



**Huntington's
Disease
Association**

Newsletter

Summer 2020

A message from Cath Stanley, Chief Executive

"I think spring / summer 2020 will be remembered by many of us for a long time, for all the wrong reasons. I know that many of you have lost loved ones to COVID-19 and others have faced the difficult and painful situation of not being able to visit loved ones in residential settings. I know that has been incredibly difficult to cope with and a situation I can personally identify with.

Our charity has worked hard to support you during these times, constantly updating and changing information on the COVID - 19 section of our website. In an ever-changing situation, we have tried to constantly adapt the information as advice changes.

We had to take the difficult decision to postpone all face to face contact, this was in line with government guidelines but more importantly to protect those people with Huntington's who are more vulnerable to the virus. Another incredibly difficult decision we had to make was to take advantage of the government's job retention scheme and furlough staff from all sections of the organisation. Not a decision we made lightly

as we are aware of how vital their support is.

However, making these decisions early into the pandemic put us in a stronger position and will enable us to continue supporting families in the future. We have been able to assess how to work differently, so we can open up more opportunities for families affected by Huntington's to receive our support. Online training, webinars, carers groups and zoom family visits are just some of the ways we have been able to innovate to support during this crisis. COVID-19 has had devastating consequences for many people but we in the Huntington's community know that Huntington's does too and will continue to once this crisis has passed. That is why it's so important that the community works together to get through this... and we know we will."

Cath Stanley

Chief Executive

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Plants, jams and a love of fundraising

Fundraising is such an important part of life at the Huntington's Disease Association, we rely a lot on the fundraising activities of our fantastic supporters but raising money is also hugely meaningful for those carrying it out. In this article, we hear from Alison who describes how she adapted to raise funds for us and why she started fundraising in the first place.

"Since my husband, Chris, was diagnosed with Huntington's disease eight years ago, and the Huntington's Disease Association, in the shape of our wonderful local adviser, Carol Dutton, came to our rescue when we were in a state of shock and bewilderment, this has been our charity of choice. For several years I read with wonder and admiration of other people's fantastic fundraising efforts, running marathons and cycling from John O'Groats to Land's End, and felt sad that I wasn't young or fit enough to do the same. Then it dawned on me that my

garden was producing seedlings that I didn't need and that I loved making jam and marmalade, and I wondered if I could raise some funds by selling plants and jams!"

"We have a wide drive and live near a popular spot for walking and fishing so have plenty of passing trade on sunny weekends. I first set up my stall about four years ago and over time have raised well over £1000. It's a great way of meeting neighbours and friendly people, and everyone is very honest, putting their money into our letterbox if no one is around to take it. One year, with help from our family, we sold drinks and cakes as well, and later this year I hope to add bric-a-brac, books and DVDs to the stall as a friend has moved recently and passed me quantities of stuff she couldn't take with her. Pricing and setting up the stall is quite time-consuming but the rewards and counting up your takings at the end of the day far outweigh the effort involved and it's great to have found a way to support such a worthwhile cause."



Alison and Chris

👉 We thank Alison and Chris for their inspiring story! If you're like Alison and feel that physical activity is not the best option for you to fundraise, then take a look at our [fundraising ideas web page](#) for alternative ideas.



Huntington's research in the time of COVID-19

Professor Hugh Rickards, Neuropsychiatrist from Birmingham and Solihull Mental Health NHS Foundation Trust, provides us with an update on the current state of UK Huntington's disease research in the time of COVID-19.

"Huntington's research in the UK has been significantly affected by the COVID-19 pandemic. There are lots of reasons for this. The main reason initially was that many research nurses were immediately diverted from research work to front line clinical care. At the same time, most research departments in big hospitals diverted all their efforts towards COVID-19 treatment and vaccination. This is not just the nursing and doctoring staff but all of the administrative support too. Finally, almost every hospital closed its doors to all except acutely ill patients.

The UK has been particularly badly hit for a variety of reasons, partly because the lockdown was relatively late in the UK and partly because of limited capacity within the health service. The good news from this is that the global Huntington's trials have stayed on track for the most part. As an example, Germany has managed to keep all its research sites open and they have a lot of trial participants. We are not anticipating any significant delays in the reporting of results on the

worldwide gene trials.

Now that the tsunami of COVID-19 is receding, we are starting to look around at what remains and get on with the rebuilding process. All the main Huntington's researchers in the UK meet on a monthly basis (along with the Huntington's Disease Association) to talk about problems and try to solve them quickly. Around the UK the picture is really variable, different towns and cities all have their own unique research environment. Many centres paused their gene trials (although some have managed to continue treating) and all centres stopped the ENROLL-HD study initially. At our last meeting, the first site in the UK had just been given the green light to restart ENROLL-HD and now three more have the go-ahead to restart, so the rest of us are writing to our organisations with the message "if they can do it, why can't we?!"

There has been some discussion about whether or not some of the ENROLL-HD study could be completed online but this is not going to happen at this stage, mainly because most countries haven't had to pause their studies.

With the gene trials, there are still hurdles for restart in some places. For instance, in Birmingham, the research facility is dedicated to the Oxford vaccination trial at the moment, a silver lining is that this study is going really well. Once



the other non-COVID-19 trials are ready to get back into action, we will have to join an orderly queue with researchers looking at cancer, heart disease and a range of other diseases who want to re-start their studies too.

In general, the picture is a hopeful one. There has been no indication from the main companies sponsoring clinical trials that there will be significant delays in getting any effective treatments to "market" because of COVID-19. Those of us in the community who are concerned with being able to access effective drugs once they are licenced are taking the time to really concentrate our efforts on this subject, which I think is still likely to be the highest hurdle to jump in the end.

In the medical community, we're itching to "get started" again as soon as possible and we can see light at the end of the tunnel now."

A massive thank you to Professor Rickards for supplying this update. We hope that this has put minds at ease and answered some questions about Huntington's research and COVID-19.

Get involved!

Online carers meetings

Caring for someone with Huntington's disease can be emotionally and physically challenging and very isolating. Because Huntington's is a rare condition, it can be difficult to meet and talk with other carers who understand the issues you are facing. Due to measures taken to combat COVID-19, this situation has been made even more acute.

In response to this, we have set up monthly online Zoom meetings to give carers the chance to meet up, chat and share advice and support - all without having to leave home.

If you care for someone with Huntington's disease and would like to join a carers meeting or learn more about it, please contact Specialist Huntington's Adviser, John Gregor on **0790 092 2522** or email john.gregor@hda.org.uk



Dates for the diary

Juvenile Huntington's Disease Weekend

Our ever-popular Juvenile Huntington's Disease Weekend will be back in 2021 over the weekend of the 4 - 6 June, so get the date jotted down. We will be taking bookings soon.

Family weekend and AGM 2020

Due to COVID-19, it is with great regret that we have made the decision to postpone the Huntington's Disease Association's family weekend 2020 until the 15 - 17 October 2021. Please put the 2021 dates in your diary, it promises to be a fantastic weekend! Travelling from America to join us is our old friend Jimmy Pollard, who will be our keynote speaker, and Simon Noble, CHDI's Scientific Director who will provide a Huntington's research update.

We will be holding a virtual AGM in which voting members will get the opportunity to submit questions and vote by proxy. This will be on Wednesday 18 November 2020, 6.30 pm - 7.30 pm and will take place online via Zoom. Formal notice of the AGM can be [found on our website](#).

Nominations for election to the board of trustees will close on 21 September 2020. Enquiries about the application process and criteria should be addressed to trustees@hda.org.uk. The board is particularly looking for nominations from people with communication and marketing skills and campaigning and lobbying skills.



Find peer support

We have a fantastic selection of branches and support groups up and down the country. Since COVID-19 lockdown, many have been taking their meetings online, offering opportunities of support to those who may not be able to leave the house. If you need support or advice on living with Huntington's from people in a similar situation, take a look at our [branch and support group web pages](#) and find out if there's a group in your area.



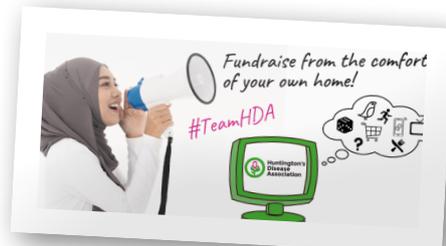
Virtual fundraising activities

The Great North Run Reimagined

The Great North Run Reimagined is the free virtual version of the UK's second-largest running event. The aim is to make the event as realistic an experience as possible so that you'll be inspired to lace up your trainers and complete the 13.1 miles on your own, with your friends, family or colleagues (socially distanced of course). [Learn more on our website](#).



Did you know that you don't have to leave the house to fundraise for us? You can hold a virtual fundraising event and increase knowledge and understanding of Huntington's disease whilst at the same time raising vital funds to support our work. We have many ideas for virtual fundraising events and activities, [visit our website for inspiration](#). During the time of COVID-19, we need your support more than ever. Contact our fundraising team at fundraising@hda.org.uk for advice.



Eating and Huntington's disease - four ways to eat well

There are an array of things to consider when thinking about eating and Huntington's disease. Good nutrition is essential for health and well-being, however, health conditions caused by Huntington's can put a strain on the body. People living with the disease will often be at risk of not getting enough nutrition and losing weight. This is due to using up lots of energy whilst also decreasing food intake, this is called the nutrition gap.

How and why does Huntington's affect diet and nutrition?

Huntington's causes many symptoms that are different for each person, some common symptoms that affect diet and intake of food or drink include...

- Chorea movement
- Stumbling or clumsiness
- Poor concentration and short term memory lapses
- Depression and mood changes
- Communication issues
- Muscular changes
- Swallowing problems

These symptoms affect the diet and nutritional intake of someone with Huntington's disease because they may experience...

- Increased energy expenditure
- Changes in appetite
- Dry mouth
- Communication and cognition issues
- Muscular changes or weakness

How to cater for this?

Avoid foods that may be hard to swallow including...

- Stringy and fibrous foods, like pineapple, celery and lettuce.
- Foods that have a skin, like peas, grapes and baked beans.
- Mixed consistency foods, like soup with lumps, stewed fruit, mince with thin gravy and muesli.
- Crunchy foods, like toast, crisps and flaky pastry.
- Hard foods, like nuts, seeds and chewy sweets and toffees.
- Husks, like sweetcorn and grains.

1



2

Think about different ways to prepare food, for example...

- Chopping, mashing or mincing food, where possible.
- Removing lumps of fruit, vegetables and potato with a fork, masher or stick blender.
- Using a blender or food processor to mince meat and chicken into smaller, more manageable sizes.
- Varying flavours by adding soy sauce, Worcester sauce, tomato ketchup, curry powder or herbs and spices to savoury dishes, and jam to sweet dishes.



3

Eat a healthy, balanced diet, including...

- Breads, cereals, potatoes, pasta and rice for energy, vitamins and minerals.
- Meat and fish for protein, vitamins and minerals.
- Fruits and vegetables for protein, vitamins and minerals.
- Milk and dairy foods for protein, vitamins and minerals.
- Foods and drink high in fat and/or sugar for energy.



4

If symptoms occur that exert a lot of energy, try eating a high-fat diet to avoid weight loss and the nutrition gap. For example...

- Instead of three main meals a day it may be easier to try smaller meals and snacks every two to three hours.
- Prioritising food which is high in calories and protein means that even if a small amount of food is managed, vital nutrients can still be absorbed.
- Similarly, using full-fat milk or cream as an accompaniment to cereals, puddings and drinks is an easy way to increase protein and calcium intake.
- Adding extra butter, cheese or mayonnaise to savoury meals, and syrup, sugar, jam or honey to sweet snacks, is a good way to add calories to a meal.
- Drinking with a meal can decrease appetite, so should be monitored or avoided altogether.
- Regular snacks like biscuits, chocolate and crackers should help keep weight up.
- Fortified drinks based on full-fat milk, such as Complan, are commercially available and can be added to meals to increase energy and protein intake.
- Keeping a food diary can help a health professional identify where there may be areas that need attention. Details like portion size and the way that a meal is cooked can be incredibly helpful.



 We have a full **Eating Well Guide with more useful information on diet and nutrition in Huntington's disease.** [Visit our website to download your copy for free!](#)

GET INVOLVED AND SUPPORT

Face coverings available now

We have Huntington's Disease Association branded snoods and face masks available for you to purchase via our [online shop](#). We have chosen several eye-catching designs to keep you looking stylish when out and about. Masks are priced at £4 and snoods at £10. The purchase of these face coverings helps us support those affected by Huntington's disease during this difficult time.

Educational webinars for all

To continue providing advice during COVID-19 lockdown, we have been taking a lot of our work online, this includes hosting a selection of informative online webinars every month. [Visit our website](#) to register or to keep up to date with future sessions.

Order Christmas cards now!

This year's selection of Christmas cards are now available to order via our online shop, they will be dispatched from September onwards. [Order yours via our online shop](#) or call us on 0151 331 5444 to order cards over the phone.

Speaking of Christmas! Keep an eye out over the coming months for our very special and exciting Amaryllis Christmas campaign.

Carol singers
—
Cats

Christmas wreath
—
Children

Dog outside gift shop
—
Christmas candles

Nativity
—
People ice skating

Robin
—
Santa



Why your donation is so important

COVID-19 has had a big impact on the way we support people affected by Huntington's disease, but COVID-19 doesn't mean Huntington's disease stops. The Huntington's community faces the same challenges it did before COVID-19. However, it now faces those challenges in a different and new world. A world with stringent social distancing measures and greater pressure on health and social care services, leaving Huntington's families feeling even more isolated and vulnerable than before. Our advisory service has seen an increase in demand with our staff working with multiple agencies to ensure families receive accurate and up-to-date advice and get the support and care they need.

Despite not being able to meet face to face, we are still there to provide support to those that need us as we did for this recent caller to our advisory service,

"It has made me feel so much less worried knowing a Huntington's Disease Association adviser is at the end of the phone or there to answer an email when things get tough as they often do with Huntington's disease. All the emotions you go through as a whole family having that support is so important to me and my whole family, not sure what I would do without it especially during these uncertain times."

Your donation today will help us continue providing advice and support through our Specialist Advisory Service, informative and educational website content, supportive social channels, welfare grants and much more to anyone affected by Huntington's disease.

[Donate here](#)

Contact us

If you need advice, information or support about Huntington's disease please contact us on 0151 331 5444 or email info@hda.org.uk

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We'll be there

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